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Informal caregiving in multiple sclerosis patients: data from the Madrid demyelinating disease group study

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Abstract

Purpose: To describe the profile of Multiple Sclerosis (MS) patient caregivers and assess their caregiving burden.
Methods: A total of 91 MS patients, recruited from a Spanish longitudinal survey, and their corresponding caregivers were studied. Caregivers were administered a questionnaire that collected social and demographic data, and a generic caregiver burden interview (the Zarit scale). Furthermore, MS patients were administered a specific health-related quality of life (HRQoL) instrument (the modified Spanish version of the Functional Assessment of Multiple Sclerosis).
Results: 24.5% of the sample required caregivers to perform activities of daily life. Caregiver profile was as follows: 67% female; mean age, 51.5 ± 14.1 years; and mean daily time devoted to care, 11.5 ± 8.2 h. Most caregivers had some type of support, 67% informal and 31.9% formal. The amount of time spent in caring for relatives was the main item determining the burden of MS-patient caregivers. Moreover, MS patient's HRQoL showed a moderate inverse correlation with caregiver burden.
Conclusions: In contrast to previous studies, most Spanish MS-patient caregivers are female, and there is a considerable percentage of parent caregivers. A greater degree of formal support and an improvement in MS patients' HRQoL may serve to reduce caregiver burden.

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Introduction

Multiple Sclerosis (MS) is an inflammatory, demyelinating disease of the central nervous system. It is the second leading cause of neurological disability in young and middle-aged adults.[1–2] The disease follows an unpredictable course over several decades, often with episodes of remission and exacerbation, but typically results in a progressive decline in functioning. Although MS may cause a wide variety of symptoms, motor, sensory, and mental disturbances are the most common.[1–2]

Diagnosis of MS obliges the patient to adjust and cope with new life-style changes and restrictions.[3] Not surprisingly, MS patients are at increased risk for depression, especially as the disease progresses and becomes more disabling.[4] However, the impact of MS is not solely confined to patients. Thus, the progressive and unpredictable nature of MS creates an uncommonly stressful life event for families.[5]

Family members are usually burdened with a variety of direct and indirect caregiving tasks that may disrupt normal family life as well as daily work.[6] Besides the strain caused by providing personal care, the changing needs and losses associated with an uncertain and unpredictable outcome may enhance the burden experienced by caregivers.[7–9] Furthermore, as families reorganize and rise to the challenge of caregiving, they need to implement new coping strategies to deal with the new and complex situation. The ability of caregivers to effectively cope with and mobilize support resources in order

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to assist with the demands and strains of the caregiving situation may finally affect their own personal health and satisfaction with their family and lifestyle.[10]

Although the burden of informal caregiving and support for disabled people has received increasing attention in the last two decades, especially in elderly people[11–14] and demented patients,[15–19] little information exists on caregiving for MS patients.

The aim of this study was threefold: firstly, to describe the profile of Spanish MS-patient caregivers; secondly, to assess caregiver burden in a series of MS patients recruited from a hospital outpatient study; and finally, to analyse the relationship between caregiver burden and variables such as care needs, patients' health-related quality of life (HRQoL) and social support.

Methods

SOURCE OF SUBJECTS

The survey covered a total of 91 MS patients who met the criteria for clinically definite MS,[20] along with their corresponding caregivers. This sample was drawn from a larger sampling frame of 371 MS patients who had been recruited at 13 Madrid Hospital Neurology Outpatient Clinics and were participating in a longitudinal study on MS-based HRQoL and social problems. A more detailed account of the background of this survey and the study population has been reported elsewhere.[21] The results of our study form part of the baseline survey designed to obtain a defined cohort of MS patients. The sample ensured representation of the types of MS patients usually found in epidemiological surveys.[22–28]

In line with the literature,[29–32] a primary caregiver was defined as the proxy who dedicated a minimum of 1 h per day to the care of an MS patient. Accordingly, only 91 proxies of the 371 MS patients met the primary-caregiver criteria.

INSTRUMENTS

All MS patients were administered a protocol that contained items concerning social and demographic data, possible existence of home and/or neighbourhood architectural barriers, reliance on technical help or help from other persons in activities of daily life (ADL), influence of MS at an occupational or work-related level, and presence of a primary caregiver.[21, 33] Moreover, all the subjects were administered a modified Spanish version of the Functional Assessment of Multiple Sclerosis (FAMS) quality of life instrument.[21, 34] This FAMS quality of life instrument version consits of 52 items divided into six subscales: (a) Mobility (seven items), (b) Symptoms (14 items), (c) Emotional Well-being (seven items), (d) General Contentment (eight items), (e) Thinking/Fatigue (nine items), and (f) Family/Social Well-being (seven items). Unlike the original version,[34] raw scores were computerized so that for all questions a high score reflected low quality of life. Each of the three seven-item subscales has a possible score range of 0 to 28; the eight-item General Contentment subscale a possible score range of 0 to 32; the nine-item Thinking/Fatigue subscale a possible range of 0 to 36; and the 14-item Symptoms subscale a possible range of 0 to 56. Neurological impairment and disability were measured using the Kurtzke Expanded Disability Status Score (EDSS). The EDSS, a widely accepted measure of neurological disability and impairment, is an ordinal scale ranging in 0.5 point increments from 0 (normal neurological examination) to 10 (death due to MS).[35]

Caregivers were interviewed using a questionnaire covering social and demographic data, relationship with the patient, daily hours of care, care at night, influence of MS on the caregiver's occupational life, drugs for caregiver depression, and support received from other members of the family and/or paid caregivers. Lastly, the modified Spanish version of the Zarit Caregiver Burden interview was administered.[36] This is a 22-item scale that assesses the lifestyle, emotional, physical and social consequences of caring for elderly relatives with dementia.[37] This scale showed good realibility and internal consistency values; a factorial analysis was carried out showing three main factors: (a) burden, (b) rejection, and (c) competence. Realiability analysis showed a Cronbach's alpha of 0.91 for the total caregiving burden scale. Finally, an analysis of construct validity showed strong correlations of caregiving burden with mental health status of the carer assessed with GHQ[38] and deviant behaviour of the patient.[37]

The study was formally approved by the Móstoles General Hospital Research Ethics Board.

DATA ANALYSIS

Statistical analysis was performed using a microcomputer version of the Statistical Package for Social Sciences (SPSS, Chicago, IL), with 5% taken as the significance level.

All items referring to MS patients and primary caregivers (percentages, frequency, mean and standard deviation) were targeted for descriptive statistical analysis, as well as the FAMS domains and Zarit Caregiver

Burden interview scores. We used Pearson's product-moment correlation with a two-tailed test of significance to study the association between the 'Zarit scale' and quantitative items. To assess the relationship between patient characteristics (including HRQoL), caregiver profile and burden of primary caregiver (as measured with the Zarit scale), we followed the conventional approach, using multiple regression models to estimate the magnitude of the independent effects. Owing to the conversion of the dependent variable (Zarit scale burden/no burden) from numerical to binary, we used multiple logistic rather than linear regression.

Results

DESCRIPTION OF MS SUBJECTS

Table 1 shows the socio-demographic descriptive statistics for the overall sample of 371 respondents with MS, i.e., mean age was 39.1 ± 10.9 years, the majority were women, 59.8% were married and 94.3% lived in a house or apartment with their family.

Table 2 shows the clinical and functional characteristics of the total sample of patients**.** Mean time of duration of diagnosis was 7.3 ± 5.9 years and patients were distributed over the range of MS disease course and symptom severity (as per the EDSS scale). Need for regular help was reported by 18.8% of subjects, a figure that rose to 33.4% in certain specific cases. Of those who had jobs, 66.9% said that MS had influenced their work lives.

Table 3 sets out the socio-demographic characteristics of patients having and not having a primary caregiver in their daily lives. Of MS patients with a primary caregiver, 67% were married and 97.8% lived in a house or apartment with their family.

Table 1 Socio-demographic characteristics of total sample of patients

Background variables	*Values* (%)	(N)
Gender		
Male	31.3	116
Female	68.7	255
Mean age	39.1 ± 10.9	
Civil status		
Single	31.4	117
Married	59.8	222
Widower	2.4	9
Separated/divorced	6.2	23
Characteristics of living		
Alone	5.7	21
With family	94.3	350

Table 2 Clinical and functional characteristics of total sample of patients

Background variables	*Values* (%)	(N)
MS disease course		
Relapsing–remitting	69.5	258
Secondary progressive	21.6	80
Primary progressive	8.9	33
EDSS scores		
0–3.5	58.2	216
4–6	24.0	89
6.5–9.5	17.8	66
Duration of diagnosis (mean ± SD)	7.3 ± 5.9	
Existence of architectural barriers	48.5	180
Regular help	18.8	70
Occasional help	33.4	124
Help required in walking	42.9	159
Help required in ADL	52.3	194
Influence on work life	22.4	83

Table 4 indicates that a total of 91 MS patients usually needed a caregiver to perform ADL (24.5% of the overall sample). Mean time of duration of diagnosis was 9.4 ± 7.6 years, with 72.4% needing regular help and 27.6% needing occasional help. Most MS patients with primary caregivers (93.4%) had no gainful employment since they were unable to work, while those who were able to work stated that MS had influenced their work lives. There were important statistically significant differences between the two types of patients (with and without caregivers) in all items.

Table 5 shows the results of the modified Spanish version of the FAMS instrument applied to MS patients, with and without primary caregivers. Higher FAMS scores mean a higher HRQoL. The mean scores for each of the domains as well as the overall FAMS scores were lower for MS patients with primary caregivers than for those without informal caregivers (with statiscally significant differences), and for the total sample of patients.

PROFILE OF INFORMAL CAREGIVERS

Table 6 lists the main characteristics of caregivers attending to the needs of MS patients. Most caregivers were women, mean age 51.5 ± 14.1 years, and the leading type of relationship was that of spouse. The mean number of years of caregiving was 7.6 ± 5.0 and the mean daily time devoted to care by primary caregivers was 11.5 ± 8.2 h. Most caregivers were helped in their caregiving tasks by some family member and, in addition, almost one third had the help of a professional (mostly on a paid basis, though in some cases provided by the city council, local or regional authority).

Table 3 Sociodemographic characteristics of patients with and without primary caregivers*

Background variables	*Patients with primary caregivers (N = 91)*		*Patients without primary caregivers (N = 280)*	
	(%)	(N)	(%)	(N)
Gender				
Male	39.6	36	28.6	80
Female	60.4	55	71.4	200
Age (mean ± SD)	45.16 ± 11.58		36.87 ± 9.87	
Civil Status				
Single	24.2	22	33.9	95
Married	67.0	61	57.7	161
Widower	3.3	3	2.1	6
Separated/divorced	5.5	5	6.4	18
Characteristics of living				
Alone	2.2	2	6.8	19
With family	97.8	89	93.2	261

*In this table the comparations between the items have no statistically significant difference.

Table 4 Clinical and functional characteristics of patients with and without primary caregivers

Background variables	*Patients with primary caregivers (N = 91)*		*Patients without primary caregivers (N = 280)*	
Duration of diagnosis (mean ± SD)*	9.4 ± 7.6		6.59 ± 5.02	
MS disease course*				
Relapsing-remitting	16.5	15	86.8	243
Secondary progressive	61.5	56	8.6	24
Primary progressive	22.0	20	4.6	13
EDSS scores*				
0–3.5	6.6	6	75.0	210
4–6	31.9	29	21.4	60
6.5–9.5	61.5	56	3.6	10
Existence of architectural barriers*				
Regular Help*	78.0	71	38.9	109
Occasional Help*	72.4	63	6.5	7
Help required in	27.6	24	93.5	100
walking*	95.6	87		
Help required in ADL*			25.7	72
He/she has gainful employment*	6.6	6	38.2	107
			42.1	118

*In this table all the comparations between the items have statistically significant difference ($p < 0.001$).

Table 5 Spanish-version FAMS (Functional Assessment of Multiple Sclerosis): domains and scores

Items	*Range*	*Patients with caregiver Mean ± SD**	*Patients without caregiver Mean ± SD**	*Total patients Mean ± SD*
Mobility (seven items)	0–28	6.4 ± 5.7	18.8 ± 6.5	15.8 ± 8.3
Symptoms (14 items)	0–56	33.9 ± 8.7	38.7 ± 9.8	37.6 ± 9.8
Emotional well-being (seven items)	0–28	14.6 ± 8.3	21.6 ± 5.5	19.9 ± 7.0
General contentment (8 items)	0–32	14.9 ± 8.4	23.9 ± 6.3	21.7 ± 7.9
Thinking and fatigue (nine items)	0–36	18.4 ± 9.0	23.3 ± 8.6	22.1 ± 9.0
Family/Social well-being (seven items)	0–28	19.6 ± 5.4	22.4 ± 4.6	21.7 ± 5.0
FAMS total (52 items)	0–208	126 ± 36.3	166.7 ± 34.9	156.7 ± 39.3

*In this table all the comparations between the FAMS dimensions of patients with and without caregiver have statistically significant differences ($p < 0.000$).

Table 6 Characteristics of caregivers of MS patients

Background variables	*Values* (%)	(N)
Gender		
Male	33.0	30
Female	67.0	61
Mean age	51.5 ± 14.1	
Civil status		
Single	13.2	12
Married	73.6	67
Widowed	12.1	11
Separated/divorced	1.1	1
Relationship with MS patient		
Spouse	53.8	49
Parents (mainly mother)	28.6	26
Sibling	5.5	5
Offspring	8.8	8
Other	3.3	3
Mean time of caregiving (years)	7.6 ± 5.0	
Mean daily time devoted to care (hours)	11.5 ± 8.2	
Work-related changes	27.5	25
Treatment (anti-depressive drug)	13.2	12
Help from other family members in caregiving tasks	67.0	61
Use of paid help in caregiving	31.9	29

ZARIT CAREGIVER BURDEN INTERVIEW

The perceived caregiver burden was rated according to the scores for the modified Spanish version of the Zarit Caregiver Burden Interview.[37] The cut-off used, as well as the obtained scores in the 91 caregivers are: less than 46—no burden: 49 (53.8%); 46 – 54—mild burden: 20 (22%); more than 54—severe burden: 22 (24.2%).

Correlation between the above Zarit scale and the main quantitative items showed statistically significant associations for some FAMS domains, as well as the daily amount of hours and the number of years devoted by caregivers to caring for MS patients (see table 7).

Table 7 Correlation between total Zarit Scale score and other items

Items	*Correlation coefficient (Pearson)*	*Sig. (2-Tailed)*
Years of caring for MS patient	0.330	0.001
Hours spent by caregiver in caring for MS patient	0.439	0.001
Mobility (FAMS)	− 0.255	0.015
General contentment (FAMS)	− 0.285	0.006
Thinking and fatigue (FAMS)	− 0.212	0.044
Family/social well-being (FAMS)	− 0.353	0.001
FAMS. Total score	− 0.292	0.005

Logistic regression was performed using the Zarit scale as the dependent variable and the following items as independent variables: EDSS score, FAMS domains (mobility, symptoms, emotional well-being, general contentment, thinking and fatigue, family/social well-being), total FAMS score, years caring for MS patient, work-related changes experienced by the primary caregiver, and duration of MS (in years). Only the item 'years caring for MS patient' proved significant.

Discussion

This study analyses the general problems faced by MS-patient caregivers, with the main emphasis on perceived burden. In view of the scant number of published studies, our research should prove useful in terms of increasing the knowledge base on this group and taking the appropriate measures. The results serve to highlight the fact that patients' HRQoL was linked to caregiver burden and that, unlike other countries, in Spain most MS-patient caregivers tend to be female.

Our sample was recruited in line with other epidemiological studies on MS patients in Spain[22–28] and these results can therefore be extrapolated to MS-patient caregivers nation-wide.

The study was conducted using direct interviews, since this method not only allows for correct implementation of questionnaires in cases where the cultural level is low, but also avoids bias due to subjects failing to answer or answering only partially.[39]

Close on one third of all MS patients needed a primary caregiver to help them with ADL. Our results show that

patients with carers had different characteristics to those without informal caregivers, in that: mean age was higher; over 90% had an EDSS score of above 4; 83.5% had secondary or primary disease course vs. 13.2% for patients without primary caregivers; and they had a keener perception of architectural barriers and the need for daily help. The explanation for these differences between the two groups lies both in the greater disability of MS patients with caregivers and in associated features (such as progressive disease course, higher age and longer time diagnosed with MS, higher scores on the EDSS scale).

Our findings for patients with caregivers were comparable to those of other studies on MS patients and caregivers.[29, 40–41]

Nevertheless, the caregivers in our survey showed differences as against their counterparts in other studies in terms of demographic characteristics. Hence, the percentage of females and mean age were both higher and the percentage of spouse caregivers lower than the figures reported by most of these other studies.[6–8, 30, 40, 42–44] Possible explanations for such differences are: (a) the high number of female caregivers may arguably be due to Spanish cultural characteristics, which reinforce the role of the woman as the caregiver for all members of the family, something that is gradually changing but nonetheless remains a deep-rooted feature of Spanish society;[45] (b) this reliance on women goes to explain the high variability in the relationship between caregiver and care receiver (for instance, high percentage of mother/wife caregivers) and the relatively lower number of spouses.

Further caregiver features worthy of mention are: (a) the length of time that caregivers had been caring for their relatives, a period exceeded by only two other studies[42–43] and possibly ascribable to the average time of duration of diagnosis (7.3 ± 5.9 years) and the functional disability of most of the patients in this survey (61.5% $>$ 6.5 on the EDSS scale); (b) though not reflected in consulted studies on MS-related care, work-related change is an aspect mentioned in research into caregivers of dementia sufferers[46–48] and indicates that burden of care can exert an influence on the occupational or professional life of the caregiver; (c) use of antidepressive treatment for caregivers is an item that is hardly mentioned in other MS studies, yet such data can point to the existence of depression, an illness reported in some research;[41] (d) social support, in the form of help from other family members in caring for the MS patient, is an aspect that has not only been described but, in the case of Spain, shows that family structure constitutes an important source of support for the caregiver, inasmuch as it can enhance caregivers' well-being and diminish their burden;[42, 49] (e) use of paid help in caregiving is low compared to the position elsewhere,[40] indicating that formal care is still poorly established in Spain.

The Zarit Caregiver Burden interview was used to measure the emotional and physical burden borne by caregivers of MS patients. Though applied in many surveys on dementia, this tool had never before been used for the purposes of MS. We sought to compare caregiver burden for MS-versus dementia-sufferers, and to assess the performance of the Zarit scale when applied to MS.

It should be noted that just over half of all caregivers reported perceiving no burden (as per the designated cut-off). If our outcomes are compared to those of other studies on caregivers of demented patients,[36, 46, 50–51] it would seem (to judge by the Zarit scale score) that caregivers of MS patients feel less burdened than do caregivers of dementia sufferers. This might be due to the fact that MS is a disease with less cognitive impairment than dementia; cognitive impairment being something that in itself generates a greater burden.[52–54] Moreover, in dementia there are more behavioural disturbances than MS, a factor which serves to accentuate caregiver burden further still.

For statistical analysis purposes, the Zarit Caregiver Burden interview was used as the dependent variable. The main item that determined MS-patient caregiver burden was the number of hours spent in caring for relatives, a finding in line with those of other studies.[30, 41, 55] What is new in this study is the relationship observed between HRQoL and caregiver burden. The modified Spanish version of the FAMS was used to measure HRQoL, with total FAMS score and FAMS domains of mobility, general contentment, thinking and fatigue, and family/social well-being showing an inverse association with burden. These data indicate that improvements in HRQoL are likely to lead to a decrease in caregiver burden.

Conclusions

The results yielded by this study suggest that a reduction in time devoted to caring for MS patients would serve to enhance caregivers' well-being, and that this would be feasible if more day-centres and formal caregivers were provided by the public authorities. In addition, HRQoL is a factor in caregiver burden, particularly in the dimensions of thinking, fatigue, family, mobility and contentment. Accordingly, it would seem advisable for fully integrated health and social services to be made available to MS patients and caregivers alike.

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